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ABSTRACT

A multifactorial model of phases in the development and progress of physical illness is described, and the model's utility is illustrated. The model consists of antecedent and concurrent conditions and consequences related to physical, psychological, and social factors and their interaction. The application of the model is illustrated by a theoretical discussion of childhood asthma and by a case study of a young adolescent presenting muscular weakness in which it was extremely difficult to delineate the parts played by physical, psychological, and social factors in the causes of the affliction. (RH)

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Selected Papers

Unit for Child Studies

Number 19

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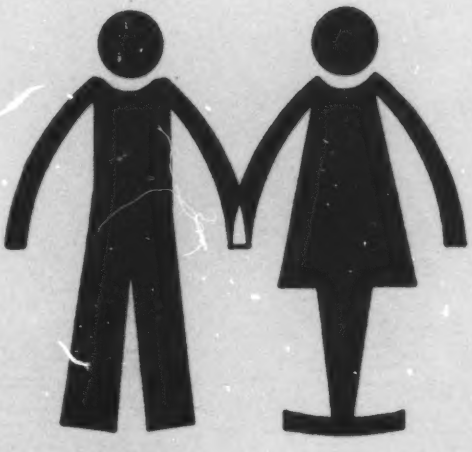

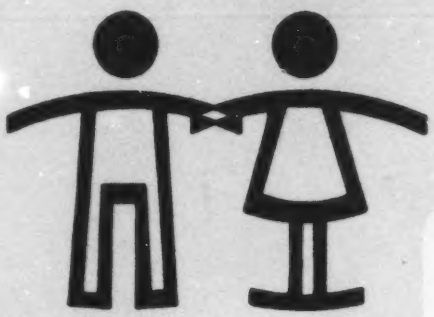

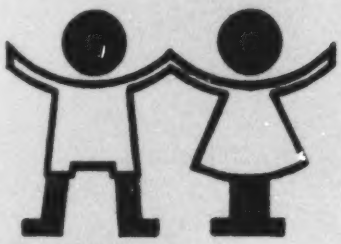

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ILLNESS IN THE FAMILY: OLD MYTHS AND NEW TRUTHS!

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ILLNESS IN THE FAMILY:

OLD MYTHS AND NEW TRUTHS!

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The relationship between family functioning and illness in a family member is a very complex one indeed. Basically, however, two subdivisions can be made. First, there is the concept that illness may be the result of abnormal family life, and secondly, there is the almost universally accepted fact that illness in the family, whatever the cause, affects the way in which the family functions. Traditionally, illness has been separated into physical and mental illness, although it can be argued that the division is an artificial one.

The relationship between mental illness and family life has been exhaustively debated. Until relatively recently, claims were made that abnormal family function might be the major factor in the causation of schizophrenia, one of the most serious forms of mental illness. Recent research indicates, however, that the most important underlying cause of schizophrenia is the genetic make-up of the individual (Heston, 1970). The possibility that life experience may affect the emergence of this condition in a genetically predisposed individual remains a possibility, but almost certainly such environmental influences have only a small role to play. Nevertheless, the effect of family functioning on the subsequent health and adjustment of an individual who has developed an illness such as schizophrenia may be crucial. It would seem, for example, that schizophrenic patients cope better in families where emotional life is relatively quiet and undemonstrative, as opposed to being turbulent and unpredictable (Vaughn & Leff, 1976). A much more widely held belief has been that the less severe mental disorders such as neuroses, are the result of stressful life experiences. Genetic factors were believed to play only a minor role. Recent research, however, has found little evidence to support the idea that the effect of the immediate social environment is crucial in the genesis of neurotic illness (Henderson et al., 1981).

It would seem that neurotic illness and personality disorders are the result of the interaction of genetic predisposition and early life experience. It is still the age-old question of nature and nurture; almost certainly both are important, but it is the proportionate contribution of each, and the complex way in which they interact, which is still unknown.

Some people feel that if genetic influences are important, the chance of curing mental illness is small. This is not necessarily so. After all, there are many genetically-based physical conditions, e.g., the absence or malfunction of certain organs or limbs, for which medical technology has been able to compensate artificially. The optimistic view is that one day the nature of the underlying disorders which give rise to certain forms of mental illness will be known, and it will be possible to rectify these conditions artificially. Furthermore, by appropriate child rearing methods it may be possible to minimise the effect of genetic influences.

Another important implication of these findings, however, is that there is no reason for much of the blame and guilt that families have experienced in relationship to a mentally disturbed member of the family. Here the parents have often become the scapegoats, carrying the burden of responsibility for the condition. Clearly this is, in most cases, quite inappropriate. Unfortunately, many workers in the health field have, in the not so distant past, done more to make families feel guilty, than to help them cope. The authors believe this has changed considerably for the better in the last few years. It must be stressed, however, that the role of the immediate social environment should not be underestimated in its influence on the overall picture of a mental illness. Clearly, this factor can greatly influence the severity and manageability of such a condition.

Over the last 50 years clinicians have become increasingly aware of the importance of paying attention to psychological and social factors in understanding physical illness as well as mental illness. Initially, the emphasis was on attempting to distinguish between those illnesses which had a clear-cut underlying physical cause and those illnesses which, even if they presented with physical pathology, were believed to have an underlying psychological cause. These latter conditions were described by the term "psychosomatic" and early pioneers in the field were Dunbar (1946) and Alexander (1952). Illnesses included in the psychosomatic category were peptic ulcer, rheumatoid arthritis, hypertension, asthma and ulcerative colitis. Despite much enthusiastic and dedicated effort on the part of many investigators, however, no really persuasive evidence has been produced to support the enduring notion that psychological variables have an unequivocal role to play in the aetiology of most of these conditions in the absence of other organic and genetic factors. Few clinicians, however, would now doubt the extreme importance of the role of psychological and social factors in influencing the course and outcome of most illness, regardless of the initial cause, Therefore. the modern trend is not to separate illnesses with a purely physical aetiology from those believed to have a psychological and social aetiology, but indeed to consider all illness as psychosomatic in the sense that physical, psychological and social factors play varying roles in every case. Lipowski (1969) stated:

> *"We have had to try to understand how the patient experiences his illness regardless of its cause, how he copes or fails to cope with it, how the family interaction is affected by and in turn evolves and gives rise to conflicts, and a host of other pertinent issues."*

The interaction of physical, psychological and social factors is important in the aetiology, subsequent course of and final outcome of any illness.

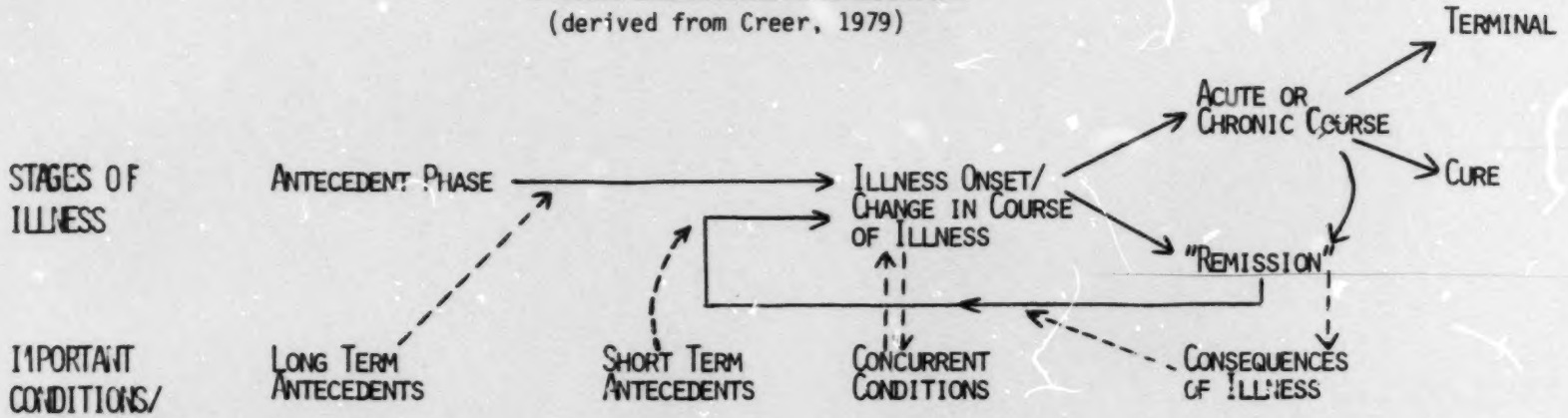
Thomas Creer (1979) describes a model which illustrates this with regard to respiratory disorders. We are of the opinion that this model has relevance to any physical illness as shown in Figure 1. Creer describes three overlapping sets of factors which refer to phases in the development and progress of physical illness:

1. *Antecedent Conditions*

   These refer to any factors or conditions which are causally related to the original onset of the illness, or to any subsequent changes in the course or progress of the illness. Broadly speaking, these factors can range from a specific viral or bacterial agent through to characteristics of a person's physical environment; and from aspects of lifestyle such as medication abuse or smoking behaviour, through to major emotional factors and family disharmony. On the basis of this model, therefore, it is assumed that a diversity of

MULTIFACTORIAL MODEL OF ILLNESS

(derived from Creer, 1979)



EXAMPLES

- Viral/bacterial agents	- Trauma	- Understanding of illness and its management	- Effect(s) on patients emotions, self concept and self esteem
- Organic factors	- Organic factors	- Health care attitudes and behaviours	- Sick role and illness behaviour
- Environmental stimuli	- Physical stimuli	- Emotional concomitants	- Lifestyle change(s)
- Lifestyle factors	- Psychological and behavioural stress	- Adherence to treatment	- Effect(s) on family and friends
- Personality factors			- Physical sequalae
- Social and family environment			- Sexuality

FIGURE 1

factors are relevant to the onset and progress of most illnesses.

2. Concurrent Conditions

These are behaviours or reactions which occur concurrently with the illness or in conjunction with a particular episode or a change in the course of the illness. They include the patient's and family's immediate emotional responses to an acute medical crisis, whether medical help is sought, and attitudes towards such help.

3. Consequences

Here we are referring to the more long term physical, emotional, behavioural and social effects of the illness on the patient, family, friends and the community at large.

There obviously can be considerable overlap among all these factors at the three different levels outlined. Stress and anxiety in a particular individual may be important at all three levels - for example, as an antecedent condition for an asthma attack, as an immediate reaction to an attack and as a longer term consequence of being an asthmatic child. Not only is this model useful in terms of understanding illness and the impact it may have on the individual and those around him or her, but it also allows one to pinpoint difficulties being experienced by patient, family or health care workers in the management of particular health problems. Understanding these in the context of the total illness experience is of help to therapists in formulating possible strategies for overcoming these particular problems.

The application of this model will now be illustrated, first by a theoretical discussion of childhood asthma, and secondly, by a case study of a young adolescent who presented with muscular weakness, where it was extremely difficult to delineate the parts played by physical, psychological and social factors in its causation.

CHILDHOOD ASTHMA

> *"Bronchial asthma is a syndrome characterised by episodes of obstruction to an adequate exchange of air in the lungs. Its clinical manifestations include wheezing respirations, dyspnoea, cough, and excessive mucus production. The changes in the bronchi and bronchioles which cause these conditions are mucosal edema, hypersecretion of thick mucus and contraction of bronchial smooth muscle, all of which result in a reduction in the lumen of the bronchial tubes."* (Alexander, 1981)

Virtually all workers in the area now accept that psychological factors have at least some part to play in the aetiology, progress and treatment of this complex and often disabling condition. The incidence of asthma has been variously estimated to be anywhere between 2 - 20% with the most realistic figure being somewhere around 5% (Davis, 1972). Of these, roughly 60% are less than 17 years of age. The fact that about 3% of all children are afflicted with the disease makes it the most common chronic disease of childhood (Travis, 1976).

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Antecedent Conditions

When examining the long term antecedents leading to asthma, the literature strongly indicates that a substantial proportion of asthma symptoms can be attributed to immunologic mechanisms and to a lesser extent, a cluster of non-immunologic pathogenic organic factors such as hyperirritability to the airways, exercise and infection. Despite much enthusiastic and dedicated effort on the part of investigators with a psychosocial bent, no really persuasive evidence has been produced to support the enduring notion that psychological variables play a large part as long term antecedents to asthma. Psychological and emotional factors, however, can certainly be important as immediate antecedent conditions to asthma attacks: and there is evidence that psychosocial variables may be capable of actually affecting pulmonary reactions in some individuals (Alexander, 1981). As well, various behavioural reactions can be important in triggering asthma attacks. Examples of such reactions are laughing, hyperventilation and breath holding, which often occur in conjunction with the presence of other physical stimuli or allergens.

Minuchin and his co-workers (1975) have described the possible role of family dynamics in the course of childhood asthma. They suggest that certain transactional characteristics may occur in families with conditions such as asthma. These characteristics are enmeshment, over-protectiveness, rigidity and lack of conflict resolution.

They state that these characteristics "provide the context for using illness as a mode of communication". The sick child has a role of enabling the family to avoid impending conflict by having an asthma attack. A ready source of reinforcement of symptoms is, therefore, provided. Minuchin and his colleagues describe three patterns of conflict avoidance. In "triangualtion" the child is put in the position of having to side with one or the other parent. Having an asthma attack, however, avoids this conflict. In parent-child "coalition", the child tends to move into a stable coalition with one parent and protects his position by his asthmatic condition. If the excluded parent becomes overtly hostile, the child protects itself with an attack of wheezing. In the third type of conflict avoidance pattern, described as "detouring", the parents are united but direct all their underlying conflict on to the sick child either by over-protecting or blaming the child.

Another possible important antecedent variable related to the course of the illness is how strictly the child adheres to all aspects of his/her treatment regimen which may include medication, recommendations concerning exercise and general lifestyle change. This is commonly referred to as compliance, and in the case of childhood illness is often mediated through a parent and thus is readily influenced by emotional problems or family disharmony.

Concurrent Conditions

The set of behaviours that can occur concurrently with, or in reaction to, asthma attacks are often ones which in the longer term might be expected to interact with treatment and the consequent health of the patient. Anxiety, panic and fear are common responses to an asthma attack, which can produce further hyperventilation and, in turn, increase the severity of the attack. Other children have particular phobias or other behaviour patterns associated with hospitals or medical procedures. Families, on the other hand, may over-react to situations and seek medical attention precipitously.

Consequences

The way in which the child and his/her family respond to a particular asthma attack is often a reflection of the way in which they cope with the illness in the longer term. When looking at the impact of asthma on the individual, this is generally described in terms of (1) emotional impact, typically anxiety and depression; (2) cognitive impact on an individual's self esteem and self concept; or otherwise in terms of (3) behavioural impact on the individual's total lifestyle or aspects thereof, with the asthmatic child often being described as withdrawn and isolated or preoccupied with bodily functions. In trying to understand the way in which a physically ill individual may behave in the context of his or her social environment the terms "illness behaviour" and "sick role" have been developed. Parsons (1951) described the sick role by pointing out that the sick individual is exempted from normal social responsibilities and from responsibility for the illness, on the conditions that he/she is expected to want to get well and to seek treatment. Exemption from normal social responsibilities for an asthmatic child may, for example, include being excused from attendance from school or being given extra time to meet scholastic assignments.

Herzlich (1973) stressed the important variable of social participation. If this is diminished the patient experiences illness as a destructive process, whereas, if it is maintained, the patient will, at best, take on the full challenge of illness and at worst, find an appropriate niche within society.

Pless et al. (1972) quote Wright's model (see figure 2) which summarizes the way in which the presence of a chronic physical disorder may affect first the child's concept of himself/herself, then his/her outward behaviour and finally, his/her mental health. This model further postulates that family functioning is a major influence in this chain of events which, in the case of a child with asthma, occurs not so much in response to the original onset of the illness, but more in response to the chronic sequelae of the condition, e.g. obesity, lack of growth, delayed sexual development and changes brought about by medication.

It is clear from the discussion so far that there are no finite boundaries between the three phases described and that the factors outlined at each phase often interact with each other. Traditionally, individual health care workers have taken over responsibility for a particular aspect of the patient's overall management, adopting single treatment approaches such as medication, physiotherapy, behaviour therapy, biofeedback, family therapy and supportive counselling. The authors have found that it is often necessary, not only to use a number of individual treatment approaches in conjunction with one another, but also to have periodic sessions where all the key health workers meet together with the patient's immediate family to discuss the overall course of the illness and its management. This then leads to the setting of more appropriate and realistic goals for each of the various individual therapies. The model for understanding illness that we have described provides a useful framework for such an interdisciplinary approach, and is well illustrated in the following case study.

RELATIONSHIP BETWEEN HEALTH, FAMILY AND PSYCHOLOGICAL ADJUSTMENT. A CONCEPTUAL MODEL

(Pless et al., 1972).

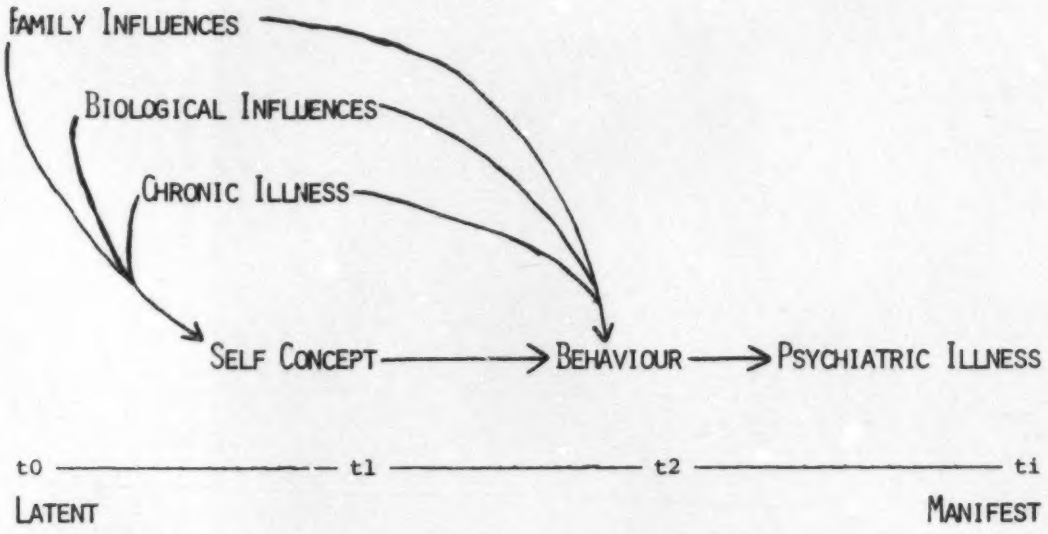

FIGURE 2

CASE STUDY - John, age 14 years

(The personal and demographic details in this case study are fictitious)

BACKGROUND

John lived with his family in a large coastal town. His father owned a retail shop and worked long hours. His mother who had previously been a nursing sister before her marriage had recently returned to work in a local nursing home. John related well to his parents and fairly well to his two older sisters. They sometimes felt that he was spoilt, especially by his mother. She had lost her first child, a son, as a result of a cot death and had been delighted that her fourth child was a boy. The girls, Sarah aged 18 and Jane aged 20, tended to enlist father's support when arguments arose in the family. The parents had a basically good relationship although there were arguments centred around privileges accorded to John. Father felt that mother was more lenient and easy going than she had been with the girls - an opinion with which they readily agreed. John was well liked by his teachers and fellow pupils. He was an average student but had no great scholastic aspirations. In fact, he had little idea aboutwhat career he wanted to take up. He was much more interested in sport and especially in athletics. He had great ability as a sprinter and held the state record for the 100 metres. He trained religiously every morning, getting up at 5 am and going to the local park with his father who kept meticulous records of his times. Father accompanied him to every track event and found it hard to hide his disappointment if his son did not win. Most of John's spare time was spent in training and he only spent a limited amount of time with his friends. He had recently become interested in girls, but had not had any girlfriends as such.

THE ILLNESS

John's previous medical history was unremarkable having consisted of the usual childhood illnesses and minor ailments. John's health problems started when he first complained of pain in his right foot after running a particularly hard race which he had won. The next day he complained that it was painful to bear weight on his right foot and he became acutely anxious that he was going to miss the State qualifying races in two weeks time. His father and mother became acutely anxious too, and it was decided to get a medical opinion. Unfortunately, the family general practitioner who was a great friend of the family was on holiday and so John was taken to the Casualty Department of the local hospital. There, a recently qualified resident noted pain on movement of the foot and ordered X-rays. He interpreted the X-rays as showing a fracture of a small bone in the foot. The foot was strapped and John was told that it would heal in about three weeks time, but meanwhile, was not to put any weight on it. John was bitterly disappointed that he would not be able to take part in the forthcoming races and his father shared this disappointment. John became depressed and moody. He stated that he could not go to school because his foot was too painful for him to go up and down stairs from one classroom to another. After three weeks the foot was no better and mother decided he should see an orthopaedic surgeon whom she had known during her nursing career. The orthopaedic surgeon reviewed the X-rays and was unable to find any evidence of a recent fracture. He told John that there was no longer any need for strapping. The surgeon further stated that there was no reason why John could not walk and advised him to do so immediately. When John said that he was unable to walk because of pain, the surgeon looked very sceptical giving a sideways

glance at his Resident. John felt resentful and humiliated. His parents looked embarrassed and tried to jolly John along with a false cheerfulness. On the way home John hardly spoke and when he reached home he went to his room and locked the door. He refused to come out for dinner. In fact, he took to his bed and stayed there for the rest of the week. He said that his leg was too painful to stand on. Furthermore, he complained that his foot was particularly painful when it was in the bed and that the bedclothes made it extremely sensitive. He therefore let the leg hang over the side of the bed. Tensions began to occur in the household, particularly between John's parents. Mother tended to be over protective and supportive and frequently mentioned the possibility of various medical conditions. Father became angry trying to minimise the problem stating that John was "going through a phase" and that he would soon "come out of it". John began to complain of other symptoms including pain in the neck and occasional pins and needles in the fingers of both hands. After four weeks both parents agreed that they would have to seek further medical help and the general practitioner arranged for them to see a consultant neurologist. By this time the leg was swollen and blue. The neurologist noted that the calf muscles of John's right leg were wasted and that the foot was hypersensitive. His neck was painful on movement. No other neurological signs were found. The neurologist said that he would have to do a number of investigations and that it would be easier to do these if John became an inpatient. He intimated to John and his parents that he wanted to make sure that there was not a lesion in the spinal cord. When asked what he meant by "a lesion" he said "Well, it could be a tumour although this is probably very unlikely". Investigations at the hospital were essentially negative. There was a very minor variation on one of the X-ray studies of the spinal cord but the radiologist had reported this as within normal limits. The neurologist stressed the importance of John putting his leg up in a cradle to reduce swelling but depsite considerable encouragement from the nursing staff he refused to do this. The social worker noted that the parents, especially mother, were "over protective". The team decided that the illness was "largely functional" and a psychiatrist was asked to see John. The psychiatrist felt that the degree of disability could not be understood purely in terms of a psychological cause. He noted that John was very depressed and angry, and that he continually complained that if it were not for his bad leg he would be running in the State Championships. He could find no evidence of an underlying psychological problem or any difficulties either at school or at home. He was non-committal in his opinion and no plan of management was suggested. John went home and over the next 12 months continued to see the neurologist as an outpatient. The neurologist's opinion fluctuated. When pressed by John and his parents he would still cling to the possibility that there might be a spinal tumour present. This opinion seemed to be based on the minor variation shown by the spinal cord studies even though there was no clinical evidence to suggest such a diagnosis. He commented that it might take a very long time for the tumour to show itself. John remained depressed and withdrawn. His parents began to squabble more and father spent more time at the hotel. Sarah decided to live in at University and Jane moved in with her boyfriend. Family life revolved around John's "bad leg". By now he was nearly 16 and had missed a whole year of school. The neurologist decided to get a second opinion and sent John to the nearest major teaching hospital where he was admitted to a specialised neurological unit. All investigations were repeated and again, all were negative. The neurologist told John and his parents that there was certainly no question of there being a serious lesion such as a tumour, stating that the spinal cord studies were absolutely normal. John's parents were relieved but John was unable to accept this and constantly reiterated that the previous neurologist had said that it might take a long time for a tumour to become manifest. Why otherwise did he still have these symptoms? A diagnosis of "reflex sympathetic dystrophy" was made. It was explained that this condition is rare in young people but has been reported after fairly minor injury and consists of swell-

ing, pain and discolouration of the limb. The treatment would be to block sympathetic nerve supply (which controls blood supply) with a local anaesthetic and if this were successful to cut the sympathetic nerve supply to the limb. The result would be a warm pink dry limb. When John asked whether this would relieve the pain the neurologist was non-committal. Meanwhile, a psychiatrist had been asked to see the patient. He was impressed by the extreme anger and hostility shown by John. He noted, as had the previous psychiatrist, that John had persistently expressed his wish to return to running and that it was only his "bad leg" that prevented him from doing so. The psychiatrist felt that this was fairly significant. It seemed that after an 18 month break John was unlikely to return, at least in the near future, to competitive running. The psychiatrist felt that it was John's unwillingness to accept this that prevented him from making progress. Co-operating in a rehabilitation programme would, for John, serve only to emphasise the reality of the situation. The psychiatrist was also impressed by the nursing staff's comments that John refused to keep his leg elevated. The neurologist was sure that this was a major contributing cause of the swelling and colour of the limb. The psychiatrist noted that John was, by now, immature for his age, dependent on parents and hospital, and that he had little contact with his peer group. He recommended that the sympathectomy be postponed until some more counselling had been done with John in order to further explore his thoughts and feelings. However, the operation went ahead. A warm dry limb resulted, but the pain persisted and so did the hypersensitivity. The doctors were pleased but John was disappointed and angry that he still had pain. One week later the limb was swollen and discoloured again, presumably because John was still hanging it over the side of the bed.

Up to this point, the neurologist had backed a physical cause for the condition and the psychiatrist a psychological one, maintaining that the condition was an hysterical reaction. The psychiatrist was not able to say what the underlying cause was, but suggested "it had to do with John's ambivalent feelings about competitive running". He also stated that there might be a deeper sexual conflict which was being repressed. Clearly, neither the neurologist's nor the psychiatrist's explanation was adequate, in the sense that neither was leading to a successful plan of management. An analysis of the problem along the lines of the model discussed will now follow.

Long-term Antecedents

1) Possible constitutional predisposition to development of reflex sympathetic dystrophy

2) Possible aggravating effect of strenuous exercise in a person so predisposed

3) Possible underlying psychological problems which typically occur in adolescence

4) Personality - especially significant that much of John's self esteem was based on his ability as an athlete

5) Parents overprotective attitude

Short Term Antecedents

1) The minor injury which occurred on the race track

2) Many of the concurrent conditions that follow served also as antecedent conditions for the stepwise deterioration that occurred in John's health.

Concurrent Conditions

1) John's anxiety - initially related to athletic performance and later to serious disease

2) The first neurologist's expressed opinion that there was a serious underlying condition, possibly a tumour

3) Parents' anxiety

4) John's persistence in hanging his leg over the side of the bed

Consequences of Illness

1) Termination of John's athletic career

2) Plummeting of John's self esteem

3) Termination of John's formal education

4) Termination of John's contact with his peer group

5) Delay of normal psychosocial maturation

6) Deterioration in parents' relationship and premature departure of John's sisters from the home

7) Development of dependency on health care workers

8) Becoming identified as a neurological patient and being exposed to surgical intervention

Management Plan

In the case described, there was clearly no identifiable single major cause for the condition. Furthermore, a complicated chain of events had developed and the end result was a severe and chronic, physical and mental health problem. After analysis of the problem as described above, therapy took on a different form. John was transferred to a Unit which catered for adolescent patients with predominantly physical illness, but where staff were particularly experienced in the management of the psychosocial problems characteristic of adolescents. Therapy consisted of:

1) Intensive physiotherapy from a very experienced nursing sister. This occurred much more frequently than had been done previously i.e., every few hours throughout the day. This was a rigorous programme and no excuses or manipulations were allowed to interfere with it.

2) Regular sessions with a psychiatrist aimed at helping John to come to terms with the fact that returning to a healthy state was an attainable goal but might not include a return to competitive athletics. Also gentle probing was done to try and identify any psychosocial problems which might be preventing John from relinquishing the sick role.

3) Regular sessions were held with John, his parents, the neurologist, the ward sister and the psychiatrist. These were aimed at improving communication between all parties concerned and setting appropriate goals for treatment. The parents were encouraged to become active therapists in the management of John's problem looking toward the time when he would be discharged. Both John and his parents had to go through a major reappraisal of the nature of John's illness.

Outcome

At the stage of writing, John's leg was functioning at a near normal level. He was walking perfectly although hesitant about trying to run. He still complained, however, of pain in the neck. The stage had been reached when he was ready to leave hospital and return home and it was hoped that he would return to school when term started in a few weeks time. However, there was still considerable ambivalence on John's part about this, and more work in preparation for this needed to be done. The team felt that the parents' overprotective attitude and difficulty in resisting John's demands, and at times manipulative behaviour, would be a major stumbling block. They still seemed to find it hard to understand that the ultimate condition had been more the result of the chain of events that followed the original injury, rather than the result of some major underlying disease process. They still, at times, referred to the first neurologist's opinion that there could be such an underlying disease process. When John complained of pain and appealed for their sympathy, they would quickly retreat to this position. They also had feelings of guilt and these tended to potentiate this attitude.

Clearly, John's prognosis is uncertain. It is interesting to reflect how different the course of events might have been had a multifactorial approach to the problem been adopted right from the outset. It is interesting that in one joint session, both parents and John commented that had their own trusted general practitioner been available at the beginning, subsequent events might have been very different. It seems possible that his advice, reassurance and medical management of the problem, based on a broader knowledge of the family, might have consisted of a very different approach from that which followed the first visit to the local hospital.

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